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TITLE: Motivations of Participants in the Citizen Science of Microbiomics. Data from the British Gut Project

RUNNING TITLE: British Gut Project: Participant Motivations

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MANUSCRIPT

Motivations of Participants in the Citizen Science of Microbiomics. Data from the British Gut Project

ABSTRACT

Purpose

The establishment of databases for research in human microbiomics is dependent on the recruitment of sufficient numbers and diversity of participants. Factors that support or impede participant recruitment in studies of this type have not yet been studied.

Methods

We report the results of a survey aimed at establishing the motivations of participants in the British Gut Project, a research project that relies on volunteers to provide samples and to help fund the project.

Results

The two most frequently reported motivations for participation were altruism and solidarity. Low education level appeared to be a recruitment obstacle. More than half of our 151 respondents said they would participate in further citizen science projects. 38% said they would not participate in a similar project if it was for-profit, or in a project that did not release datasets in repositories accessible to scientists (30%).

Conclusions

The desire of citizens to take part in research was reported as a key motivation for participation in BGP. Such prosocial motivations can be mobilized for the establishment of large datasets for research.

Introduction

The establishment of databases for research in human microbiomics poses important recruitment challenges. The inter-individual diversity of microbiota composition is vast and the microbiome is a dynamic research object that changes in response to environmental, physiological and pathological events.[1 2 3] Microbiomic studies require large cohorts, repeated sampling from the same individuals, rich phenotypic data, and dynamic behavioural or clinical annotation.[4 5]

The American Gut Project (AGP) and its British offshoot, the British Gut Project (BGP), have used a 'citizen science' approach to establishing a database on human microbiomics.[6] Citizen science is a broad label under which a wide range of practices are subsumed, ranging from volunteers contributing money or collecting data to volunteers running an entire project without the involvement of professional scientists. In the particular instance of the AGP and BGP, the projects employ a "thin" model of citizen science where the project's goals and methods are determined by professional scientists. Volunteers are enlisted to contribute samples and funding. While there are other, more "robust" practices and understandings of citizen involvement in science[7], the BGP is similar to citizen science projects in the natural sciences, where lay people contribute to the collection and annotation of data (e.g. environmental data, species observations, etc.).

The gut projects use FundRazr, a dedicated crowdfunding platform. In fact the AGP and BGP are among the platform's most successful campaigns, recently hitting the $1m threshold). Upon subscription to the platform and payment, volunteers receive a swabbing kit that they must return per mail. Within a few weeks, they receive their test results online. Standard analysis includes information on microbial species found in a person's gut, and how this person's gut microbes compare to those of other individuals. The project emphasizes that test-takers should not take their personal results as clinical advice.

Data are de-identified and released through the European Bioinformatics Institute (EBI), member of the International Nucleotide Sequence Database Consortium (INSDC).[8] Test takers can access their own raw data using a unique identifier code.

The BGP thus combines features of direct-to-consumer (DTC) genomic testing, i.e. the sale of tests directly to paying consumers without the involvement of clinicians, and citizen science, in the sense that "lay" people participate in research tasks. Unlike with DTC genomics, the disclosure of personalized test results to users is not the main sales pitch in the case of the gut projects. The main argument in the BGP's recruitment strategy is that users can contribute to science. This raises the question of whether this model is scalable to support recruitment in other research projects in the biomedical field.

In order to answer this question we need to understand why participants decide to take part, and what their views of the BGP's aims and organisation are. To our knowledge, a study into these aspects in microbiomics has not been carried out so far (similar studies have been conducted for DTC genomics[9 10]). An ex-post survey of motivations is not a perfect way to understand why people decided to take part. It is, however, an effective way to identify important themes and values that matter to participants in connection with their participation.

Materials and Methods

In December 2015, after obtaining research ethics approval, we contacted 370 participants in the BGP who had agreed to be recontacted through a dedicated BGP mailing list. Between December 2015 and January 2016, 151 participants filled in an online questionnaire that was circulated via email and hosted by the survey service "Surveymonkey". The survey included 10 closed questions. Participation rate was 41%; the demographic characteristics of the responders are reported in Figure S1. We also obtained the aggregate demographic data of all BGP participants, which enabled us to compare the characteristics of the entire set of BGP participants to those who participated in our survey.

Figure S1. Demographics

Results

The two most common motivations for participation in the BGP were prosocial: to participate in clinically useful research (78%) and help clinicians in the search of cures for medical conditions (79%). Self-knowledge and lifestyle figured prominently but to a lesser extent: 39% declared they wanted to find a cure for their condition, while 58% and 59% respectively said they wanted to learn how to change their diet, or see whether they are healthy. Less than 20% declared that they changed their diet after obtaining results or consulted a medical doctor. Figure S2 summarises these findings.

Figure S2. Summary of results

Just over half (53%) of respondents said that they plan to participate in another CS project, and 40% said they have not decided that yet. 37% and 34% respectively said they would not participate in a for-profit project, or a project that does not release datasets in public repositories. Eight in ten respondents (82%) said that the academic nature of BGP played a role in their decision to participate. Seven in ten believed there are no risks in projects such as BGP (71%). Only 1% (n=2) said the risk is very high.

Some respondents had not received results at the time of our survey. They declared this in the comments section and left blank questions pertaining to the use of results. About one in ten said they consulted a physician as a result of undergoing the test (11%), while two in ten (21%) declared they changed their dietary habits. A quarter of all respondents (25%) said they understood their condition better after taking the test. Almost six in ten (57%) believed that their knowledge of microbiomics was sufficient to interpret results correctly.

Discussion

Findings from our research need to be extrapolated with caution to the broader set of participants in the BGP. While the majority of respondents to our survey was 65 or older, participants in the BGP are more evenly distributed across age groups. Moreover, while the participation rate was high in comparison to other comparable studies,[10] our sample size is small, and no significant associations could be found between demographic variables and answers to specific questions. It is also important to remember that participants in the survey represent a subset only of the participants in the BGP who decided to be re-contacted. The motivations and values of these participants could differ from the other participants in the BGP, since willingness to be re-contacted could be a proxy measure of a positive attitude towards being part of a citizen science project.

Participants in our study reported prosocial motivations to have played an important role in determining their willingness to participate in the BGP. Such motives are usually described as altruistic or solidaristic. Altruism is usually defined as a helping behaviour based on a broad interest to further common, pro-social goals, or as a person's prioritizing the needs of others over her own. Solidarity can be defined as a shared commitment to accept 'costs' (financial, practical, emotional, etc.) to support others with whom people recognize relevant similarities, such as a shared interest in research, or a shared health risk or experience of illness.[11 12] In other words, while altruism describes a person's disposition towards others, solidarity is a practice that draws upon and reinforces connections between people.

Prosocial motivations have been shown to underlie participation in biomedical research in the past,[13] although scholarship on this topic has been criticized as over-emphasising altruistic behaviour.[14] Against this backdrop, the notion of solidarity seems to better accommodate the simultaneity of self-interest and concern for others that has been found to motivate research participation in many studies.[15] In particular, in the contexts of data-rich medicine, solidarity has been described both as an important motive that could be harnessed to enjoin people to participate in such research, as well as a powerful way to frame such research endeavours.[16]

Also in our study, both self-interest and prosocial motivations were at play. In our case, however, direct benefits or clinical relevance of the research appeared to have played a minor role; although self-knowledge was a motivation for some participants, only a minority would have refrained from taking part if the tests had no personal health relevance. We can only speculate about the reasons for this. It could be the case that the strong citizen science rhetoric in the advertisement of the BGP, which calls upon potential participants to "help science" at the same time as they "explore their inner self" (http://britishgut.org), is particularly attractive to people looking for an opportunity to support science as an added

benefit to getting personalized results. That more than a third of our respondents said that they would not participate in a similar project within a commercial setting, or where data would not be released for public benefit, indicates that public benefit was indeed considered an important factor. A recent study on public attitudes towards commercial data use in the United Kingdom yielded similar findings. [17] It is thus possible that for projects like the BGP to thrive, an emphasis on public benefits can help with recruitment.

Another finding of our study that is relevant for the design of similar studies is that most respondents considered risks associated with participation in the BGP to be non existent or low (see Figure S2). This is an important indication that volunteers in projects such as the BGP project or consumers of DTC genomics, who have been shown to be highly educated individuals,[18] do not expect to be harmed by their participation in CS projects of this kind. Apparently participants themselves are, at least in our study, far less concerned about the risks of such projects than some outside commentators.[19] Overall, also in view of the fact that direct benefits (clinical relevance) did not play any decisive role in motivating participation, the type of project we studied appears to have a very positive risk-benefit ratio in the eyes of participants. Only 13 out of 151 respondents mentioned risks that they were concerned about. Only xx respondents described specific risks, including data leakage, failure of anonymization, bioterrorism etc., which however they did not deem significant enough to refrain from participating in the BGP.

We found that an important obstacle to recruitment appears to be age and education level, with poorer recruitment among the young and less educated (7/10 respondents to our survey hold at least a college – or comparable – degree, while the overall figure for the United Kingdom is closer to 3/10). Given that bioresources reliant on self-recruitment of participants are already biased towards the resource-rich[20], this bias may be exacerbated

further, especially in light of the accompanying crowdfunding campaigns and the financial costs that participants shoulder in these studies.

Four drivers of the well-known decline in research participation have been identified in the literature: an increase of the numbers of studies conducted; public mistrust in science; the burden of the studies for participants; and a general decrease in volunteerism.[21] Citizen science approaches can help address the three latter factors. Participatory designs can improve scientific literacy and give people more control over the aims of the study, thereby helping to address lack of trust. The burdensome nature of some studies might be countered by the desire for participation. And finally, in addition to utilizing new forms of digital interaction, our data indicate that decreasing volunteerism could be addressed by emphasizing prosocial reasons for participation in the recruitment strategies of citizen science projects such as the BGP.

The desire of people for active participation in research can and should be mobilized and expanded. In order to ensure that marginalized groups in society are represented in studies that are likely to lead to health-related inferences at the population level, this should be accompanied by recruitment efforts tailored specifically to underserved groups, although different incentives may be required. In case of crowdfunding, several formats of participation should be offered, preferably encompassing "entry level" packages at the lowest possible cost. Overall, engaging participants more directly in funding, designing, and evaluating projects as well as in collecting samples and data could help ensure the continuation and expansion of data collection in the life sciences.

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Conflict of interests

BP is an employee of King's College London that also hosts the BGP. She has no formal connection to the BGP and does not benefit from it financially.

References

1. Lozupone CA, Stombaugh JI, Gordon JI, Jansson JK, Knight R. Diversity, stability and resilience of the human gut microbiota. *Nature* 2012; **489**: 220-30.

2. Human Microbiome Project C. Structure, function and diversity of the healthy human microbiome. *Nature* 2012; **486**: 207-14.

3. Claesson MJ, Jeffery IB, Conde S, Power SE, O'Connor EM, Cusack S, *et al.* Gut microbiota composition correlates with diet and health in the elderly. *Nature* 2012; **488**: 178-84.

4. Human Microbiome Project C. A framework for human microbiome research. *Nature* 2012; **486**: 215-21.

5. McDonald D, Birmingham A, Knight R. Context and the human microbiome. *Microbiome* 2015; **3**: 52.

6. Del Savio L, Prainsack B, Buyx A. Crowdsourcing the Human Gut. Is crowdsourcing also citizen science? *J Sci Com*. 2016; **15**(03):A03.

7. Wooley J, McGowan ML, Teare HJA, Coathup V, Fishman JR, SetterstenJr RA, Stercks S, Kaye J. Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. BMC Medical Ethics 2016; 17:**33**
DOI: 10.1186/s12910-016-0117-1

8. Su Y, Howard HC, Borry P. Users' motivations to purchase direct-to-consumer genome-wide testing: an exploratory study of personal stories. *J Community Genet* 2011; **2**: 135-46.

9. Goldsmith L, Jackson L, O'Connor A, Skirton H. Direct-to-consumer genomic testing: systematic review of the literature on user perspectives. *Eur J Hum Genet* 2012; **20**: 811-6.

10. Vayena E, Gourna E, Streuli J, Hafen E, Prainsack B. Experiences of early users of direct-to-consumer genomics in Switzerland: an exploratory study. *Public Health Genomics*. 2012; **15**(6): 352-62.

11. Prainsack B, Buyx A (2012). Solidarity in contemporary bioethics. *Bioethics* 2012; **267**: 343-350.

12. Prainsack B, Buyx A. *Solidarity in Biomedicine and Beyond*. Cambridge, UK: Cambridge University Press, (in press)

13. Stunkel L, Grady C. More than the money: a review of the literature examining healthy volunteer motivations. *Contemp Clin Trials.* 2011; **32**(3): 342-352.

14. Adams M, McKevitt C. Configuring the patient as clinical research subject in the UK national health service. *Anthropol Med.* 2015; **22**(2): 138-148.

15. McCann SK, Campbell M, Entwistle VA. Reasons for participating in randomised controlled trials: conditional altruism and considerations for self. *Trials.* 2010; **11**(1): 1.

16. Prainsack B, Buyx A. A solidarity-based approach to the governance of research biobanks. *Medical Law Review*. 2013; **21**(1): 71-91.

17. Ipsos MORI. *The one way mirror: public attitudes to commercial access to health data.* Wellcome Trust: London, UK, 2015.

18. Prainsack B, Buyx A. "Governing health databases". In Prainsack B, Buyx A. Solidarity in Biomedicine and Beyond. Cambridge, UK: Cambridge University Press. In press.

19. Heeney C, Hawkins N, de Vries J, Boddington P, Kaye J. Assessing the privacy risks of data sharing in genomics. *Public Health Genomics* 2011; **14**: 17-25.

20. Aicardi C, Damjanovicova M, Del Savio L, et al. Could DTC genome testing exacerbate reserach inequities? Hastings Bioethics Forum. Available at (Accessed 30th June 2016): http://www.thehastingscenter.org/response-to-call-for-essays-could-dtc-genome-testing-exacerbate-research-inequities/

21. Galea S, Tracy M. Participation rates in epidemiologic studies. *Ann Epidemiol*. 2007; **17**(9): 643-53.